



PATHWAYS TO HIGH ADHERENCE

Mutuality Framework



WHAT YOU WILL FIND IN THIS APPENDIX

Appendix D contains the mutuality framework that helped inform the collaborative counseling approach. Here we adapt the model to how it would apply to ring adherence.

WHO SHOULD USE IT

Using the mutuality framework can be helpful for project planners, community liaisons, and intervention developers and implementers as a way to think about how a participant may approach using a study-provided ring. The main contribution of this framework is to call attention to the possibility that even though someone may willingly engage in a study that provides rings, she may have reservations or concerns that limit her use of the ring in practice. Thinking about how communities map onto the four dimensions identified by the framework can also direct community mobilization efforts to help position the ring, agencies providing the ring, and procedures needed for monitoring ring-use safety as legitimate and trustworthy. The framework has particular relevance in communities where trust in the ring, the drugs in the ring, the research institution, or biomedical research and products in general is tentative, making people skeptical or cautious about engaging in the prevention strategy. Communities with histories of discrimination or real or perceived questionable research practices may be wary of the ring and its safety but eager to participate in a trial or demonstration project to access resources/services provided as part of participation.

HOW TO USE IT

Here we provide information about the framework. This is intended to be educational for providers, researchers, and community representatives. Different groups may use the framework in different ways. We suggest starting with a map of where participants in a given community are likely to fall among the four dynamics described below, which will help to plan for culturally relevant mobilization and engagement strategies.

MUTUALITY FRAMEWORK

The mutuality framework (Figure 5) was developed from qualitative interviews with young women in Cape Town, South Africa, who had participated in an open-label oral pre-exposure prophylaxis (PrEP) trial looking at adherence to different kinds of non-daily, as well as daily, regimens.⁸ In that work, a narrative emerged that helped explain why some people would avoid using PrEP entirely, while others would champion PrEP in their community. Specifically, four approaches to PrEP were identified: actively avoiding PrEP, being uncertain about using PrEP, being committed to trying to use PrEP, and being highly invested in PrEP.

Each of these approaches is explained by the different dynamics playing out among participants, the community, and the study. As indicated in the figure below, four dynamics are identified: distrust, uncertainty, alignment, and mutuality. Each dynamic is detailed in terms of tensions and synergies among the participant, community, and study; the resulting approach to PrEP; and implications for where and how to engage participants.

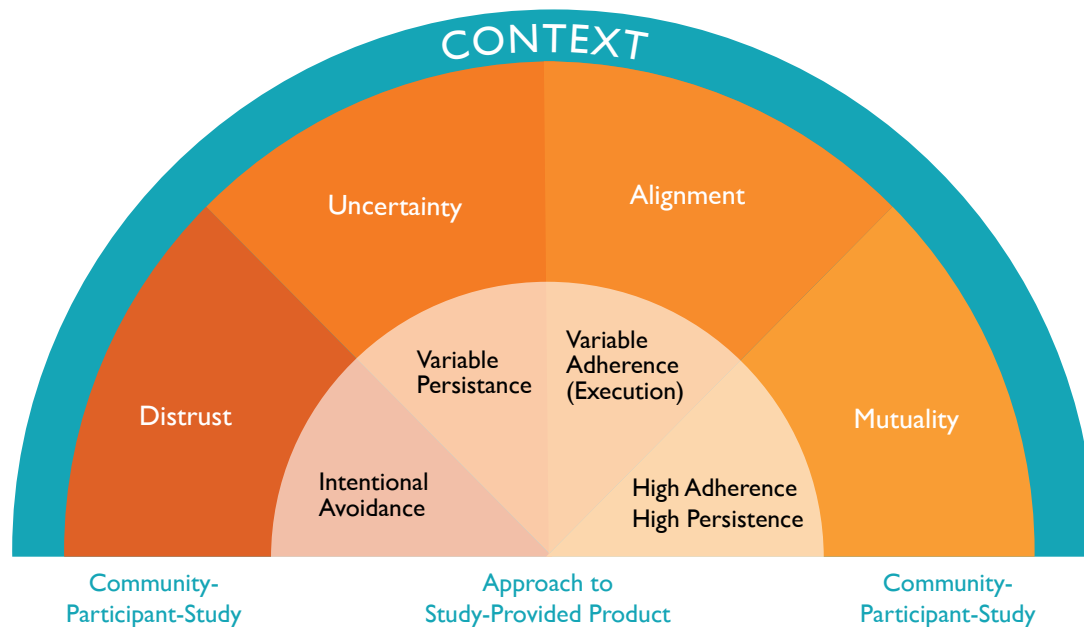
Any dynamic, regardless of what it is, is influenced by:

- Social and personal resources, whether tangible or intangible.
- Social-political history with research and site (skepticism).
- Identity attributes (e.g., self, important others, research, community) as participant or product “user.”
- World view regarding where self and community intersect. (In the case of South African women, we identified *Ubuntu*, meaning where there is a priority of one's own contributions having real benefit to one's community.)
- Product attributes, regimen burden, ease of use, and match to context.

⁸ See Amico KR. PrEP experiences among South African women in the HPTN067 (ADAPT) study: Healthy paranoia (skepticism), Ubuntu, champions and challenges to resolving PrEP dissonance. 8th IAS Conference on HIV Pathogenesis, Treatment and Prevention. 20 July 2015. Vancouver, Canada. Presentation available at: <https://www.youtube.com/watch?v=InFO2r2sO88>

FIGURE 5

Mutuality Framework: Four dynamics that describe study product use by characterizing intersections among the participant, community, and study.



DYNAMICS

Distrust:

- **Dynamic:** Rejection of integrity of stated goals of study or its benefits to community.
- **Approach to Product:** Active avoidance of study-provided product.
- **Engagement Challenge:** Avoidance of disclosure of concerns to study; may manage tension by dissuading others.
- **Intervention Implications:** Build trust and try to move toward ambivalence (e.g., through staged debates, normalization/invitation of skepticism, transparency, community and participant engagement strategies).

Uncertainty (skepticism):

- **Dynamic:** Skeptical kind of exploration; is the study and/or the study products good for self or community?
- **Approach to Product:** Variable persistence (e.g., on again/off again engagement with regimen).
- **Engagement Challenge:** Discomfort while weighing options; may not disclose concerns to study.
- **Intervention Implications:** Support exploration process; move skepticism from private to public. For example, through use of staged debates, normalization/invitation of skepticism, transparency, peer-to-peer interventions, reinforcement of efficacy (when possible), on-demand use designs, engagement of participant(s) in quality improvement procedures and evaluation of the study and study procedures (e.g., “secret shoppers or mystery clients”) to build ownership.

Alignment

- **Dynamic:** Provisional acceptance that the study and product do benefit self and community in ways that are relevant and meaningful.
- **Approach to Product:** Variable execution (e.g., high persistence, variable success with adherence).
- **Engagement Challenge:** Maintaining alignment with study while improving execution.
- **Intervention Implications:** Support of alignment; building of adherence motivation and skills (e.g., through peer support, barriers/strengths-based approaches, low-burden regimen, high-value regimen).

Mutuality

- **Dynamic:** Alignment of study goals and vision are seen as mutual; the vision is shared, and a kind of ownership of the work and advocacy in the community takes place.
- **Approach to Product:** Good persistence/good execution of adherence.
- **Engagement Challenge:** Maintaining high sense of ownership.
- **Intervention Implications:** Support of alignment; create opportunities to lead and advocate (e.g., through peer supporters, community liaisons, participant advisory panel, post-trial advocates).

APPLICATION TO RING USE

The mutuality framework can help explain the interactions women have with the vaginal ring, their social surroundings, and the agency, clinic, or site providing the rings. The dynamics described in the framework are fluid, and women may move between dynamics over time and in response to accumulated experiences with the product, her community, and providers of the ring. Consistent with the overall approach of promoting engagement throughout a woman's journey toward high levels of use, the framework also emphasizes reasons for participation, beliefs about the product and those providing it, and sense of agency, as well as the perceived congruence between what one believes about the ring and those providing it, and what one's own desires and core values are. The goal is to have women in the alignment and mutuality dynamics, and for the strategies that support movement toward those dynamics to be prioritized and to move beyond individual one-on-one discussion-based counseling with a research, clinic, or agency member. The *Pathways to High Adherence* manual offers diverse strategies — aimed to optimize overall engagement with the ring as a prevention method — that are well aligned with the mutuality framework.

